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The Nordic data imaginary

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Abstract

The Nordic countries aim to have a unique place within the European and global health data economy. They have extensive nationally maintained and centralized health data records, as well as numerous biobanks where data from individuals can be connected based on personal identification numbers. Much of this phenomenon can be attributed to the emergence and development of the Nordic welfare state, where Nordic countries sought to systematically collect large amounts of population data to guide decision making and improve the health and living conditions of the population. Recently, however, the so-called Nordic gold mine of data is being re-imagined in a wholly other context, where data and its ever-increasing logic of accumulation is seen as a driver for economic growth and private business development. This article explores the development of policies and strategies for health data economy in Denmark and Finland. We ask how nation states try to adjust and benefit from new pressures and opportunities to utilize their data resources in data markets. This raises questions of social sustainability in terms of states being producers, providers, and consumers of data. The data imaginaries related to emerging health data markets also provide insight into how a broad range of different data sources, ranging from hospital records and pharmacy prescriptions to biobank sample data, are brought together to enable "full-scale utilization" of health and welfare data.

Keywords

Big data, health data, health policy, platform economy, Nordic data gold mine, data imaginary, sustainability

Introduction

Sadowski (2019) has noted that "data – and the accumulation of data – is a core component of political economy in the 21st century" (1). The Nordic countries are aiming for a unique place within the European and global health data economy. They have extensive nationally maintained and centralized registers, health data records, as well as, numerous biobanks. Frank (2000) has even suggested that in the Nordic countries the entire population becomes a study cohort. States have also become increasingly aware and concerned about their international image as progressive and competitive, leading many to adopt nation branding strategies to gain visibility (Aronczyk, 2013; Jaffe and Nebenzahl, 2006; Valaskivi, 2016; Volcic and Andrejevic, 2016). Tupasela (2017) has argued that in many such countries, populations become a "brand" that can be marketed on international research markets, while others have suggested that the Nordic countries can be considered a "gold mine" or "Eldorado" (Kongsholm et al., 2018; Rosén, 2001). In terms of economic competitiveness, the Nordic countries regularly rank among the most competitive countries in the world (European Commission, 2017).

Some of the data-driven competitiveness discussed above can be attributed to the development of the Nordic welfare state system. More recently, however, the so-called Nordic data gold mine is being re-imagined in another context, where data and its ever-increasing logic of accumulation (Zuboff, 2015) is seen as a driver for private business development. Some have even suggested that this can be called a form of "data extraction" (Swadowski, 2019; Zuboff, 2015), or "data colonialism" (Couldry and Mejias, 2019) where data is appropriated. By accumulation and extraction

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we refer to processes by which states and other public authorities (e.g., public hospitals, public research institutions) are able to collect data on a broad range of human activity in society. The accumulation of data on these activities is registered, for example, in public hospital records, cadastral registries, national cancer registers, as well as prescription re-imbursement registries. The "logic" behind this type of accumulation lies in it being automated, systematic, and all-encompassing or complete. Unlike companies who collect data on their customers, state-collected data is based on citizenship or residence, as opposed to a customer relationship.

This paper explores the development of policies and strategies of Denmark and Finland—two Nordic countries—as they seek to gain a stronger presence in the global data economy. Using the healthcare data sector as an example, but drawing examples also from the broader data economy we seek to show how the Nordic countries are pursuing to attract global investment and collaboration. We ask how nation states try to adjust and benefit from, new pressures and opportunities to utilize their data resources in data economies. The attempts to align national data policies in emerging health data economies provide insight into how a broad range of different data sources are imagined and envisioned under a supposed harmonious national data infrastructure, which enables "full-scale utilization" of health and welfare data (Tarkkala et al., 2019). We show that being part of the global health data economy is not straightforward. States, which have traditionally had strong national data monopolies—such as the Nordic countries—find themselves in a dilemma of being both a producer, a provider, and a consumer of data. This takes place in a sphere that spans outside the boundaries of traditional governance, such as allocation of resources and services, and the related statistics. The Nordic welfare states have also been built on an ethos of fairness and equality, principles that may be problematic in relation to market forces, such as competition.

Following Zuboff's (2015) notion of *surveillance capitalism* we point out how Nordic countries *envision* wealth creation based on the logic of data accumulation. Zuboff's analysis concentrates on Google and other large companies that aim to predict and modify human behavior as a means to produce revenue and market control, while our focus is on how the logic of accumulation is planned in state-led systems of data collection in the hopes of generating new sources of wealth. The wealth that is based on surveillance can be generated in many ways: it can be either direct investment, funding for research or research collaboration, the setting up of companies or provision of services which utilize publically collected data, or a combination of these. These attempts, we argue have not been as successful as hoped. States also have numerous responsibilities toward their citizens besides financial profit, such as securing right to privacy as well as basic and human rights. In this sense, the healthcare systems in the Nordic countries represent a unique example of how states seek to appropriate data from their populations and try to find ways in which to capitalize on that data. Despite their historical and legal similarities (e.g., GDPR), Denmark and Finland are planning their data extraction in somewhat different ways and have chosen to follow different paths through which the population becomes an object of capital accumulation. The logics of accumulation also reconfigure how the sources of this data are considered and imagined. As such, data politics have taken center stage in the governance of our everyday lives (Andrejevic, 2014; Ruppert et al., 2017).

We see surveillance capitalism as being located within the broader context of imagined futures (Beckert, 2016). The Nordic countries have envisioned, like many other countries, the *platform* (Van Dijk et al., 2018) as a pervasive form in the organization of social activities to the extent that it has penetrated economic thinking as well. In these visions, the vast public data collection machineries, such as population registries, health data collected from primary and specialist healthcare services, are made increasingly available and productive for secondary purposes. In this platform economy (Kenney and Zysman, 2016) approach, data from the population serves as the basis for secondary use by extractive industries. What makes the Nordic countries different from other countries is their long-standing use of personal identity codes to identify individuals across a broad range of public and private services from healthcare and public libraries to insurance. The personal identity code enables combination of data from different sources. In the Nordic countries, the public sector is also the main provider of healthcare services. Levels of public trust and acceptance of this arrangement have also been very high giving the state further mandate to develop its operations further (Gaskell et al., 2010). It is population data, and the *potential* related to its appropriation, collection, and utilization in the platform economy that we conceive of as an elementary part of the imagined future. This imagined future sees data as a central element of improving competitiveness and reducing public costs, as well as generating new forms of wealth.

According to Beckert (2016: 273), these kinds of imaginaries gain credibility through the structure that "institutions, conventions and social power" provide, as well as their "capacity to inspire belief in a specific future." Beckert (2016) argues that imaginaries are an important part of the dynamics of capitalism, since through them "capitalism adjusts and regains its

momentum" (4). Platform economies serve as a way out of the previous, now apparently outdated ideas related to economic growth and innovations (Beckert, 2016). Similarly to the sociology of expectations, uncertainty and openness of the future are rendered as a pursuable future (Brown and Michael, 2003; Van Lente, 2012). Jasanoff and Kim (2009) have introduced the concept of socio-technical imaginaries to address "collectively imagined forms of social life and social order reflected in the design and fulfilment of nation specific scientific and/or technological projects" (120). In this paper, however, we follow Beckert's (2016) way of seeing imaginaries as elementary part of the temporal order of capitalism, which is more explicit about the role of expectations and imagining in the economy.

Methods and materials

This paper is the outcome of a collaboration between two separate, but thematically interlinked research projects in Denmark and Finland. The Danish data was collected as part of an ERC funded project (POLICYAID) where Tupasela studied the emergence and utilization of artificial intelligence platforms in Danish healthcare system (See Hoeyer, 2016). The Finnish project, Good(s) for Health: Personalized Health Services and Flexible Appropriation of Bioinformation, conducted in Finland by Snell and Tarkkala focused on what ways are bio- and health information shaped, combined, and modified to an applicable and useful form in different information contexts. Our empirical material consists of policy documents in Finland and Denmark. These include documents from ministries, as well as supranational organizations, such as the Nordic Council of Ministers. Our case selection identified similar examples of how Denmark and Finland are seeking to reorganize state-led data collection and capitalization. The examples presented give an overview of important changes taking place in the way countries are seeking to re-orient their data practices. Furthermore, we have collected field notes, including PowerPoint slides from various conferences in which a broad range of actors have presented their visions of how data ought to be extracted, accumulated, and shared within the Nordic countries.

We have applied frame analysis to examining the themes which we identified as being common between policy developments in Finland and Denmark (Goffman, 1974; Kuypers, 2009). The themes were identified in on-going discussions regarding the changes that we observed in the collected data. Drawing on abduction as an inferential process as developed by Timmermans and Tavory (2012), we identified and analyzed issues that are associated with financing the state, data extraction, citizen involvement, as well as public–private interaction in or for "full-scale utilization" of health data. Both countries have, for instance, emphasized the development of personalized medicine, which has resulted in published strategies promoting the potential of genomics (Ministry of Social Affairs and Health, 2015, 2016), as well as a joint statement for a Nordic roadmap for personalized medicine (Njølstad et al., 2019). This approach requires the systematic extraction of large amounts of health and lifestyle data of individuals from the healthcare services. Although we only focus on two Nordic countries in this paper, we argue in the next section that these developments can be seen within a broader context in which the Nordic countries are seeking to find new ways in which they can leverage their national data sources onto international markets. These attempts, however, are not straightforward, as we will show, due to the multiple commitments that the state has to maintain such as equality, fairness, and transparency. In what follows, we first present the context of Nordic data registers, data sources, and other collections as gold mines, and then move on to discuss the welfare state data as basis for platform economy.

The Nordic data gold mine

The Nordic countries have had a long tradition of collecting systematic data on their populations. In part, this practice can be explained as an outcome of the gradual development of the welfare state infrastructure from the 1960s (cf. Asda and Gradmann, 2014; Desrosiéres, 1998; Reigstad et al., 2016). Unlike most other European countries, or other countries in the world, the Nordic countries have developed state mandated population registers to generate accurate data concerning the population (Bauer, 2014; Rosén, 2001). These registers are unique in that they have a legal mandate which obliges various authorities to collect and maintain data on the population (Alastalo, 2009; Kettunen, 2001). Furthermore, they do not allow for citizens to opt-out of them since they form a central part of the functioning of the welfare state services.

For decades these registers have served administrative and scientific purposes, but more recently the interest in using them to a greater extent has attracted increased political attention to extract more economic benefits from them. One of the most ardent drivers of this process has been the Nordic Council of Ministers, which brings together all the Nordic decision-makers to coordinate and foster collaboration between the various Nordic countries. Under its various institutions, such as its research funding organization NordForsk, the council has supported policy initiatives and

research, which seek to improve Nordic collaboration in the use of data from the populations.

As early as in 2007, the Nordic Council was supporting efforts in which the Nordic countries were seen and positioned as experimental labs on a national scale. As one such report noted, the Nordic countries could be seen as a "Global Health Experimentarium" (Nordic Council of Ministers, 2018), where attempts could be made to generate new forms of value from existing resources. This type of thinking was coupled with seeking to brand the Nordic countries as a unique place where research and innovation could take place (ScienceNordic, 2011; Valaskivi, 2016). The main challenge, however, was how to coordinate and facilitate the use of data from all the Nordic countries, which despite similar histories and political agendas of developing welfare systems had their own legal and administrative systems through which researchers had to go through in order to get access to population data. This process could often be arduous and time consuming, which was seen as a major challenge in attracting outside interest and thus financing into conducting research in the region. For companies, administrative hurdles and hindrances were seen as a major obstacle to investments.

In an attempt to better understand these challenges, NordForsk funded a number of initiatives, which developed possible solutions to the problem. During the past decade alone, NordForsk has produced a number of policy briefs ranging from responsible data sharing (Nordic Council of Ministers 2013a; 2013b) to Nordic biobanks (Nordic Council of Ministers 2014; 2017a; 2017b). Within these policy briefs the notion of the Nordic countries as a data gold mine has been presented time and again (Kongsholm et al., 2018). As one such policy brief has noted:

> The Nordic countries have a unique asset in their excellent administrative registers, longitudinal data-bases and biobanks, often referred to as the "Nordic goldmine". Use of these datasets in research can produce new knowledge to improve Nordic public health and welfare. However, these registers are currently not being used to their full potential in research. There are great benefits to be gained from properly coordinating the registers for use as a joint Nordic resource. (Nordic Council of Ministers, 2014)

The notion of the Nordic data gold mine has become a popular reference point in almost all recent policy papers found in the Nordic countries relating to data. This can be explained by the fact that the Nordic data registers are indeed globally unique. Another reason for its more recent popularity can also be explained by the fact that big data has become a major political and economic preoccupation. Big data is increasingly seen as a possibility for fostering new innovations and investment, which the Nordic countries have been very keen to attract. The idea that data would become a new Nordic commodity emerges as an important theme during this time. Yet despite such visions, there has always been a tension within the Nordic countries as to the ways in which health data can be exploited and used in commercial markets without undermining people's trust in the public healthcare system.

Examples of successful data accumulation projects can be found in a number of open data projects. In Denmark, the Open data DK platform (www.opendata.dk) highlights numerous examples of how data previously collected and maintained by the state has been made open access to businesses. These include the national geodetic platform (www.dingeo.dk) that can be used for third party location services to statistical research, as well as marketing. In Finland, a similar platform on open data (www.avoindata.fi) makes numerous publicly collected and maintained data sets available for public and commercial use. Such national open data projects have served as an example or template for the secondary use of data from the healthcare sector. By developing common application control interfaces, centralized permit authorities, as well as supportive legislation, easy access by various service providers is enabled. The application of this model has proven problematic and challenging, however. Numerous concerns over basic rights, privacy, accountability questions by authorities and administrators over who would devolve control of their data sources to a single authority, as well as technical challenges over interoperability over so many data sources remain. In addition, further debate around data collection and management exists in relation to regional politics where smaller cities and hospital regions have expressed concern that centralized data management systems would make the regions no more than data providers with little access to expertise, investment, or further development of infrastructure.

Within Nordic biobanking, for example, the issue of financial sustainability has always been a challenge. On the one hand, samples and data have been a necessary pre-requisite for high-quality research conducted in public universities. On the other hand, biobanks have wanted to charge companies higher prices in order to extract profits from their activities. The problem has been that with the blurring of the line between public and private, charging higher rates to companies and lower rates to universities would be problematic in relation to competition law. As such, the vision of extracting financial gain from biobanks has encountered the problem of possibly shutting out public research institutes,

which would not be able to afford such high prices, or alternatively, selling data to companies at a discounted price. Unlike other natural resources, the "mining" of data for profit comes with a host of social, ethical, and legal issues which complicate its translation into wealth.

The translation of data into wealth has most recently also be compounded by the fact that the data economy has become more multi-sited; individuals are sharing data and sourced in a multitude of new ways by private companies. Within this environment, states no longer maintain a monopoly on large-scale data collection, but rather find themselves competing with businesses for a share of revenues to be extracted from data from the population (Sharon, 2016). In the following sections, we will examine this development in Denmark and Finland in order to better understand how they seek to integrate state ambitions with emergent data economies.

Welfare state data as national resources in Denmark and Finland

In a digital platform economy, interoperability allowed by standards, labels, protocols, and agreements is key in a technical sense (on digital platforms, see e.g., De Reuver et al., 2018). However, the overarching aim is continuous value creation by different actors such as users, service providers, and other stakeholder groups. These values, however, are not necessarily monetary. Turning different aspects of life into data—"datafication"—allows for the transformation of their purpose, as well as turning "information in the new forms of value" (Cukier and Mayer-Schoenberger, 2013: 35; Zuboff, 2015). Data, in its many forms and sources, forms an increasingly important component of this value creation. In Finland, some commentators have argued that publicly collected data, along with other data sources, offers "nearly limitless possibilities for the development of new kind of data business" (Viitanen et al., 2017: 14). Similarly, in Denmark, Steenberg (2018) has written that "Denmark has a Goldmine of Healthcare data for researchers to explore." These types of statements can be seen, not only as a type of hype, but also as fictional imaginary (Beckert, 2016) regarding the productive power of data. To generate economic wealth and value, based on data, is simultaneously about being able to attract "generative activities associated with a platform" (De Reuver et al., 2018: 124). Thus, in a data economy, states aim not only to participate in it through their own data, but also through the creation of an ecosystem that allows for the platforms to function. The state is a producer, an enabler, as well as a consumer of data. In this sense, the public sector has many roles. As Finnish platform economy report states:

> Companies, ministries, hospital districts and universities should be from now on developed as networks that exchange information, that interact with their environments. We do away with our own silos and move towards improving productivity by opening our own interface and combining our knowhow, data and networks with the ecosystems of partners seeking fast growth. We organize ourselves to generate customer value with common platforms. (Viitanen et al., 2017: 9) (Own translation)

The report was commissioned by the Finnish Government, Prime Minister's Office, Ministry for Economic Affairs and Employment, as well as Business Finland with the goal to make Finland a global partner in platform economies. The report sought to offer both companies and the government insights and understanding about the potential of platforms and data. The above excerpt is part of a chapter "The Superiority of Platform Economies" in which the authors state how the platform economy is a masterpiece of digital business with continuous value creation for all participants. This excerpt highlights what Sadowski (2019) has written: "The drive to accumulate data now propels new ways for doing business and *governance*" (1). The expectation is that the ones "who can harness big data effectively will enjoy a significant edge over others" in many fronts, be it "generating economic growth, providing public services, or fighting wars" (Cukier and Mayer-Schoenberger, 2013: 35). Examples from Finland and Denmark highlight how data accumulation and data ecosystems are imagined in welfare state settings with an eagerness to harness data and benefit from it. The main challenge with these imaginaries is that there is a shortage of concrete examples or existing pathways of how health data is transformed into a wealth producing asset. The strategies and policies seek to formulate an internationally attractive environment for investors, research and development. This is done by highlighting the existence of large amounts of systematic data, infrastructure, and a favorable legal environment. This vision is what is imagined, yet it is still to be realized.

Denmark

Like most Nordic countries, Denmark has sought to locate itself at the center of the emerging global data economy. At a general policy level, Denmark published its digital strategy for 2016–2020 in which it has outlined numerous policies, which it will seek to implement in a broad range of activities in order to facilitate

further growth. Within its strategy, however, lies the realization that new tax revenue sources need to be sought and that the digital economy presents one such opportunity to find new revenue streams.

> Financing the Danish welfare system is based on the taxes and charges paid by individuals and businesses. However, digital development and new business models will also challenge the revenue models and regulatory models of the public sector. The global, digital economy is expected to grow and, in the long term, perhaps require new solutions. (Danish Ministry of Finance, 2016: 11)

The strategy seeks to identify new ways in which the state can extract value from its existing activities, as well as identify new avenues through which value can be generated.

A relatively recent example of how Denmark seeks to establish commercial partnerships with private industry comes from the establishment of Beijing Genomics Institute (BGI) in Copenhagen. Denmark does not allow for Danish tissue samples to be sent abroad, so instead of samples going abroad, Denmark was able to attract BGI to set up a sequencing facility in Copenhagen. This model of partnership highlights several important factors relevant for our examples. *First*, it is an example of direct foreign investment in a high-tech area. *Second*, it ensures that Danish samples or data is not shipped abroad, which has been a concern to the Danish. *Third*, it allows for research collaboration between Danish research groups and companies with BGI. For BGI, the benefits lie in the possibility to develop products, which they are able to market to Danish customers, as being developed in Denmark using Danish data. These products include a host of pre-natal and neonatal diagnostic kits, as well as tumor marker testing kits tailored for Danish patients. From a marketing perspective, BGI benefits from having used Danish data sets to develop their products with Danish research groups since this collaboration generates scientific publications, as well as credibility from the perspective of their customers who are medical professionals. A precondition for this collaboration, however, is that all research has to be conducted with Danish researchers at a Danish research institution, such as a university.

Although Denmark and Finland are both Nordic welfare states, their primary healthcare systems differ from one another substantially. Whereas Finnish primary healthcare is provided by municipal health centers, Danish primary healthcare is provided by General Practice physicians who own their own medical practices. Although both systems form a cornerstone of universal healthcare, the data collection systems (data extraction) between the two differ drastically. In Finland, data is collected by municipalities and the state, which have had a legal basis for the extraction. In Denmark, however, given that GPs are private practices subsidized by the state, diagnostic data has been collected in the Danish General Practitioners Database (Dansk Almen Medicinske Database (DAMD)), which was discontinued in 2014 after privacy and legal concerns emerged over its operation (Wadmann and Hoeyer, 2018). Up until its closing down, the DAMD had been considered one of the best primary care databases in the world, according to the OECD (2017). Other data sources, such as billing and prescriptions, have been collected by different actors in Denmark, such as the Regional administration. After its sudden shutdown, the database has been slowly re-starting with the implementation of specific legislation that allows disease-specific data to be collected, such as on diabetes and heart disease. The DAMD debacle, however, raised concern over the ability to collect and share population-level data regarding private GP visits. Furthermore, it points to challenges that exist in developing data collection systems, which are both transparent, respect the original collectors of data (GPs), and take into account people's wishes regarding the secondary uses of their data. The interconnections between private and public actors in data collection and sharing were not made clear enough in the original model, which is now being addressed though legislative means, which should, in principle, make the duties and responsibilities of the different actors more clear.

A third example of extraction policies in Denmark relate to the Danish National Genome Center and its relation to citizen involvement. On 29 May 2018 the Danish parliament adopted a new Act to establish the center. The purpose of the center is to serve as a national infrastructure for genome sequencing, as well as a national database for genome data (Lov om Nationalt Genom Center vedtaget, 2018). The center is part of the national strategy for personalized medicine (Ministry of Social Affairs and Health, 2016). The main focus of the strategy is on developing a transparent governance structure with nationwide involvement; this includes a clear legal structure and ethical principles, which seeks the involvement of patients and citizens. The process leading up to the establishment of the center was somewhat contentious. In the original proposal, the samples and data were to be collected using an opt-out system for participants. During the winter of 2017–2018, however, there was a lively public debate in the media where concerns were raised about this model. As a consequence of the public debate, the proposal was changed in February 2018 so that informed consent was required in order for a sample to be stored in the center (cf. Hartlev, 2015). As such, the policy in

Denmark regarding the use of genome information derived from patients was changed as a result of public opposition to the opt-out model. The Danish model, therefore, has paid attention to the role of the patient in the research and care process. As the first of six principles of the genome Center strategy states: "The Danish efforts within Personalized Medicine are to focus on the patients. Genome sequencing is to be used for the treatment purposes and in research projects" (Ministry of Social Affairs and Health, 2016: 8). As we will discuss below, this approach has focused on a different type of data imaginary compared to Finland, where patients and their information have been imagined in a different light. One challenge with the Genome Center has been its relation to the regional universities and hospitals. The centralization of the center to the capital regions has raised criticism and concern from the rest of Denmark as to how and who controls the genomic data that is generated in Denmark. As these sequences are considered important resources to research groups, hospitals, and hospital regions, questions surrounding their governance and concentration in one location are a contentious discussion point. Since samples and data equal power, their centralization in Copenhagen is not a trivial point.

In relation to the data economy, the sourcing of data from patients in Denmark presents a tension between patient and commercial interests. On the one hand, policies have emphasized the significance of the data economy in development and wellbeing. On the other hand, some policies have emphasized the significance of patient care over financial interests. At the same time, an awareness has emerged where data sourcing activities have been problematized because of the lack of legal justification for the collection of vast amounts of data. The DAMD case, for example, shows how Danish authorities have only relatively recently become aware of the intricate ways in which patient data is produced and shared. The case of BGI Denmark suggests that there are viable solutions to utilizing data to develop commercial products, but that the collaborations allowing for such developments need to be carefully regulated and managed. At the same time, the debate surrounding the Genome Center suggests how public debate has had an impact on the model of data sourcing that is adopted for genomes research. In the next section, we will discuss the Finnish case regarding the extraction of data for the data economy.

Finland

During the past years, Finland has sought to create an enabling environment for the utilization of health and welfare data collected through public services and registers. There has been a push to enable faster and more efficient use of social and health data, as well as other types of data that can be connected with each other. This is done to develop a lively data ecosystem that could feed a platform-based economy, but also to allow for knowledge management. Digitalization and the utilization of healthcare data are seen as an answer to the challenges of an aging society. This is expected to result in "significant efficacy in health care processes" as well as "support the work of medical doctors and nurses" (Ministry of Economic Affairs and Employment, 2017: 24). However, these new solutions are then expected to scale to the global markets. As a recent government report stated "well being is a growing market in western countries" (Ministry of Economic Affairs and Employment, 2017: 24).

Compared to Denmark, Finland's policies for data accumulation and its utilization have been more overarching and broader, and the goal is to bring *all* data within the remit of secondary use. One of the most prominent examples to support data extraction in Finland comes from the new law concerning the secondary uses of health and social data, which was approved in March of 2019 (HE 159/2017). The Ministry of Social Affairs and Health (2017) described the idea of the renewal:

> The Government proposes a new act on the secondary use of health and social data. The aim is to ensure flexible and secure use of data by establishing a centralised electronic license service and a licensing authority for the secondary use of health and social data.

The Law on the Secondary Use of Data was passed in the parliament after several rounds of committee hearings and even though the opposition accused the proposal of making the whole of Finland a "laboratory for experiments" (Tamminen, 2019). Unlike Denmark, however, there was very little public discussion related to the reform and its supporters often referred to a shared will in Finland to make the reform happen. The centralization of cervices has been an important driver in Finland leading to the set-up of a one-stop-shop for access to nationally maintained data sources and registers (Aula, 2019). As Korhonen et al. (2017) have argued:

> As all documentation of patient data in Finland is digitalised and as the same will soon also apply for data on social services, there are versatile opportunities for the secondary uses of health and social care information. Primary use of health data means use of the data for the purpose it has been gathered for. Secondary uses mean *all other handling and analysis of sensitive patient/customer data than what is needed for treatment, care and services received by the individual him/her*self. Secondary uses include, e.g., generation of statistics and indicators,

> research and product/service development, service operations management and planning, supervision and service system monitoring/surveillance. (33) (emphasis in original)

Within the Finnish data imaginary, all data can and should be made available through a *single platform*, where access and connection of the various platforms becomes as fluid and seamless as possible. Existing legislation was seen to be outdated and insufficient for today's needs. The old legislation did not enable the gathering of sensitive information using the personal identity code for *all* purposes that were regarded as necessary to produce efficient health and social services, as well as economic growth. The main idea of the renewal was that data should be made accessible for secondary purposes ranging from research and statistics, development and innovation, teaching, knowledge management, monitoring, to steering and official planning, thus answering to the demands of full-scale utilization of data. Other justifications for new legislation included overcoming the scattered nature of patient and customer data. As one report noted:

> The issue with integrating data from various current social welfare and health care information systems is poor compatibility and interfacing between the systems. Health and social care information system architecture has approximately 400–800 systems, with more than 500 connections between them, around 10,000 expert users and 10–100 system owners. The integration of data from this setting remains a challenge to be solved in order to unleash the full potential of the Finnish health data. (Korhonen et al., 2017: 24)

This legislative reform was supported by the Health Sector Growth Strategy (2014) which is an overarching policy framework that emphasizes Finland's potential to become a forerunner and internationally attractive partner for global business and cutting-edge research. These goals have trickled down to other strategies that are part of this policy framework, such as the establishment of a National Genome Center, a similar project that was also initiated in Denmark (Ministry of Social Affairs and Health, 2015). The preparations to establish a national Genome Centre started already in 2016, but the required legislation has not been passed yet. The governance of the Genome Centre would fall under the general umbrella set forth by the secondary use data legislation, but it has been given a considerable extension for revision due to difficulties in adapting the GDPR into national legislation. The exact form and structure of the genome center is at the time of writing this article still unclear. Its role, however, is seen as an important part of the data imaginary in Finland since it is seen as a part of the national data ecosystem.

The goal of these reforms is not just to develop an interconnected ecosystem, but to provide broad coverage of data collection. As the *Government Report on the Future* states, digitalization will "enable forming of a real time and proactive picture of people's life situations" (Council of State, 2018: 40). This is based on real time production and collecting of data, done by various actors, resulting in data on "lifestyle related for example to standard of living, education, consumption or say social relations" (Council of State, 2018: 40). This data is then combined and analyzed with the help of machine learning and artificial intelligence in order "to recognize the interventions required" (Council of State, 2018: 40). Yet, the report does not stop there, but gives an example of the scale of data that optimally could be utilized. In the future, then

> By connecting automatically for instance data about the amount of person's social relationships produced by social media, GP's data about the body-mass-index and family history regarding health, income data based on the income registry and data about the food consumption based on the data collected by the grocery store, health problems can be predicted and prevented. (Council of State, 2018: 41)

This all-encompassing vision of data accumulation is important in relation to how citizens are placed and conceived of in data imaginaries, and how states perceive emergent data economies of the future. An example of how this is being deployed can be found in a major research project called FinnGen (www.finngen.fi), which is a research collaboration between Finnish universities, hospitals, hospital districts, pharmaceutical companies, biobanks, as well as funding organizations. With more than nine pharmaceutical companies helping to fund research using multiple sources (biobanks, hospital data, populations registers, etc.), the FinnGen project represents public–private collaboration. As with Denmark, access to public data is gained through research collaboration with public partners. Such large research projects are hoped to develop templates for future research collaborations, as well as examples of how data can be used. The concrete public benefits are yet to be realized, notwithstanding the research collaboration and funding. The project is also meant to showcase for industry the opportunities that they have in terms of accessing new types of public data that they previously did not have access to.

In the next section, we will discuss the Danish and Finnish data imaginaries in relation to the logic of accumulation.

Logic of accumulation (and the imaginaries of the data and platform economy)

Zuboff (2015) suggests that surveillance capitalism forms a basis for the accumulation of data, which can then be further monetized in different ways. For Nordic welfare states, the process of capitalization is also based on the idea of turning personal and population data into commodities, but poses different opportunities, as well as challenges. We have explored this relationship in relation to Denmark and Finland. Both countries view the accumulation of data as a way of partially financing the welfare state of the future. Although Denmark and Finland share similar histories in terms of welfare state development, as well as a common commitment to developing platforms for the extraction and use of data from their healthcare systems (DAMD and Law on Secondary use of Data), they nonetheless have taken different approaches in the way they govern and administer these processes. In part, this can be attributed to structural differences in how data is collected, for example primary healthcare in the two countries. We suggest, however, that the differences can also be explained in how the national data ecosystem is organized. In Denmark, despite national policies for data extraction and use, the system remains relatively fragmented or dispersed, where control and governance are distributed among many actors, such as the regions. In Finland, however, the state's position has been to try and integrate all public data producing systems under a single umbrella so the potential data user needs to deal with only one permit authority. Denmark's approach can be considered one of national coordination, whereas Finland's a system of integration.

Both Denmark and Finland generate policy imaginaries where existing state-collected data is connected with data derived from social media platforms and other generators of private sector data. In these imaginaries, individuals and citizens are re-positioned as customers, who in exchange for their data will receive both data self-determination and better services. According to a report published by the Ministry of Economic Affairs and Employment of Finland, citizens are expected to receive "targeted and predictive services in every part of their life cycle" (Ministry of Economic Affairs and Employment, 2017: 34). There seems to be no limits to what sort of personal information can be extracted and utilizable in the quest for prediction and prevention that is framed as better services, "value," for the citizens. Concurrently, "not all value is bound to monetary exchange – a consumer can, for example, give up their data and the work put into the platform without compensation, but get one's money's worth of free service" (Viitanen et al., 2017: 17). This idea is in contrast to previous ideas inherent in welfare states, where the citizens are *entitled* to services through citizenship without underlining expectations for their data participation (see Helén and Jauho, 2003; Snell, 2019).

Interestingly, the Finnish *Government Report on the Future* (Council of State, 2018) received critical attention from the Data Protection Ombudsman, Reijo Aarnio (2018), who wrote that the "report is big brother's wet dream" as regards to the way full-scale utilization of data is imagined. He criticizes the authors of the report as lacking concern regarding "special protection of delicate information" or "informational self-determination" (Aarnio, 2018). It all comes down, in a regulatory sense, to what purpose the data was originally collected for and in what kind of relation the new uses would be compared to the original (fifth article of the GDPR, see EU, 2016). This is summarized by Aarnio (2018) in his blog text as follows: "As a rule the data can be used only for specific, particular and legal purposes, and they cannot be used later in a manner that is incompatible with those purposes."

In this sense, Denmark's more gradual approach may contain the seeds of benefit in that Finland's overarching approach to the secondary use of data may prove problematic down the road (cf. Wadmann and Hartlev, 2018). Finland's emphasis on efficiency may have benefits for the utilization of a broad range of data source, but also may be problematic in relation to the GDPR and informational self-determination of citizens. In relation to the national application of the GDPR in Finland's Data Protection regulation, Finland's approach has included national exemptions regarding administrative fines if violations of the GDPR occur. Section 24 of the national Act states: "An administrative fine cannot be imposed on central government authorities, state enterprises, municipal authorities, autonomous institutions governed by public law, agencies operating under Parliament or the Office of the President of the Republic" (HE 9/2018 vp). It must be noted, however, that how the implementation of the GDPR will be interpreted at the European level is still unclear and may take years to resolve if this is challenged in court.

It has to be noted, that parallel, but separate to the described ventures in Finland, there is a growing tendency to focus on the informational rights of the individual (Lehtimäki and Ruckenstein, 2019). However, the perspectives from the MyData movement (Poikola et al., 2015) or data activism (Kennedy, 2018) have not been integrated into the legislation concerning the secondary use of social and health data or the establishment of the Finnish nor the Danish Genome Centre. As such, the different approaches also reflect varying conceptions of data protection in

these countries. In Finland, data protection legislation is formulated more through an expert led approach, whereas in Denmark public debate plays more of a role.

An example of differences in data accumulation comes from the consent practices adopted or envisioned by the two countries. Data collection in the Danish National Genome Centre is based on informed consent while the Finnish Genome Centre is planned to offer an opt-out model. When a person undergoes a genetic analysis in Danish healthcare, he/she can decide whether the data can be used only for one's own personal treatment or also for research. In Finland, the genome data for the Genome Center is planned to be gathered through two routes. In healthcare, the genome data would be similar to patient records and stored automatically to the Genome Center, unless opposed by the patient. The other route would be through biobanks, where new samples are consented and old samples are not (Salokannel et al., 2019; Snell and Tarkkala, 2019). It is still unclear how the opt-out model would function and whether there will be possibilities to limit one's consent. However, opting out of the system would not limit one's access to services in any way since they are guaranteed by law. Interestingly, in both genome center models and data use, there has emerged a tension between the central authority and institution who would manage and operate the centers, and those actors which would be supplying the samples and related data (doctors, biobanks, hospitals, and hospital regions). The suppliers see that this model reduces their ability to control and fully extract and utilize the value of the samples and data. From a state and potential user perspective, however, a dispersed data ecology is problematic. As such, the national genome centers represent a re-distribution of power and authority over data and samples from regional actors to a centralized authority.

There is a delicate balance between the benefits and the potential broad extraction and exploitation of data by the state. The states have a dual role: they are simultaneously the beneficiaries of big data, but also the ones who should be aware of the dangers of the accumulation of big data and act as intermediary gatekeepers for the citizens, not for their own power per se. As Cukier and Mayer-Schoenberger (2013: 37) have reminded:

> States will need to help protect their citizens and their markets from new vulnerabilities caused by big data. But there is another potential dark side: big data could become Big Brother. In all countries, but particularly in nondemocratic ones, big data exacerbates the existing asymmetry of power between the state and the people. (37)

Although Denmark and Finland rank among the most democratic countries in the world, there is a concern regarding the data visions that they embrace. With private companies, such as Google and Facebook, individuals as customers choose which service providers you use (admittedly, some services are so pervasive that many people lack such a choice, such as with Google for example), but with the state your choices are limited and you are not a customer of the state in principle. The state merely provides the opportunity to use different service providers (doctors) within its confines, but you are obligated to generate data that is then used when you use public services. Furthermore, all medical prescriptions and re-imbursements, including those in the private sector, are logged into a database that can be used for research. This relationship, which Van Dijck (2014: 200) terms "barter," only works with companies, whereas the state's logic of data accumulation is all encompassing and complete. The recent visions by Nordic welfare states, such as Denmark and Finland, to extract more value from the data they generate, suggest that states are trying to reconfigure their responsibility, as well as accountability for data accumulation in order to benefit from the possible financial outcomes.

Conclusion

The Nordic welfare states have had a long tradition of collecting and using a broad range of nationally collected data sources in the governing of their populations. The monopoly of the state over data production and collection has become increasingly challenged by large international data companies (Ruppert et al., 2017; Sharon, 2016) and the companies are employing strategies of the new data economy that is based on logic of accumulation (Zuboff, 2015). The Nordic welfare states are not, however, willing to forfeit their reputation and position as gold mines of data. Instead, Nordic countries—such as Denmark and Finland—are trying to adjust to, and benefit from, data economies in different ways. The development of data ecosystems which cater to an increased thirst for linkable and complete data is currently the main goal, as well as challenge for the Nordic countries. Both countries seek to find a delicate balance between the benefits and the potential broad extraction and exploitation of data by the state. In comparing and contrasting Denmark and Finland, we suggest that despite similar historical backgrounds and legal frameworks, these countries employ somewhat different approaches in envisioning and implementing their data economies. For example, the role and opinion of public debate in the two countries has been significantly different, where Finland has shown less interest in accounting for public concerns

or even fostering a debate surrounding such visions (Snell and Tarkkala, 2019).

If companies can be indifferent toward the population they gather data from, as Zuboff (2015) suggests, states cannot. The relationships between the state and its citizens are based on reciprocity and dependence. However, the strategies of Denmark and Finland that aim to harness the potential of population data to enhance innovation, economic development, and competitive advantage of the nations are challenging this relationship. The imaginaries that are employed in the Nordic countries, however, help to organize activities and direct funding toward developing platforms which are more efficient in collecting, making visible, and providing access to a broad range of data sources. Efforts to revise legislation and bolster research collaboration are prime examples of how the imaginaries give rise to new ways of generating wealth from data. We therefore suggest four main consequences of these developments.

First, the development of national data ecosystems, through platform economies that converge both public and private institutions, introduces new and more complicated dependencies between the state, companies, and the data sources. The attempts to simplify the use of data through one-stop-shop systems reveal the complex and multifaceted nature of national data resources. *Second*, the way citizens are expected, and even obliged, to participate in automated, systematic extraction of data manifests itself differently in Denmark and Finland. Both of these approaches also differ from the systems created and upheld by private companies. *Third*, the growth and expansion of data regimes, which are envisioned as national ecosystems and platforms for multiple users, increases the possibilities of data divides. The rights and obligations of citizens within such systems are unclear in relation to the drive of states to increasingly extract more data from individuals. *Fourth*, public–private collaboration appears as the most efficient and trustworthy avenue through which private partners can seek to gain access and exploit publically collected data. Not only does the collaboration provide a public partner as a type of buffer, but it also lends an air of data legitimacy for the products which are being developed based on the national data.

In relation to the Nordic data imaginary, the development of national data ecosystems and platforms which increasingly support public–private collaboration can also be seen as a type of legitimation exercise for both public and private actors. For private actors, it is an opportunity to provide examples of how they can operate as trusted partners in using publically collected data in developing new innovations. For the public actors, it is an opportunity to show how they can become more flexible, dynamic, and efficient in utilizing public resources for the good of the general public. The challenge, however, remains to show, as well as define the scope of what the public good specifically and in general refers to in such collaborations.

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